

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Proposed Highly Specialised Technology Evaluation

### Recombinant human alpha-mannosidase for treating alpha-mannosidosis ID800

#### Provisional matrix of consultees and commentators

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> <li>Chiesi (recombinant human alpha-mannosidase)</li> </ul> <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> <li>Climb</li> <li>Contact a Family</li> <li>Genetic Alliance UK</li> <li>Genetic Disorders UK</li> <li>Jnetics</li> <li>Muslim Council of Britain</li> <li>Rare Disease UK</li> <li>South Asian Health Foundation</li> <li>Specialised Healthcare Alliance</li> </ul> <p><u>Professional groups</u></p> <p>Association</p> <ul style="list-style-type: none"> <li>Association of British Neurologists</li> <li>Association of Genetic Nurses and Counsellors</li> <li>British Inherited Metabolic Disease Group</li> <li>British Paediatric Neurology Association</li> <li>British Society for Gene and Cell therapy</li> <li>British Society for Genetic Medicine</li> <li>British Society for Human Genetics</li> <li>British Society of Paediatric Gastroenterology, Hepatology and Nutrition</li> <li>Institute of Neurology</li> <li>Metabolic Pharmacists Group</li> <li>National Metabolic Biochemistry Network</li> <li>Primary Care Neurology Society</li> <li>Royal College of Nursing</li> <li>Royal College of Pathologists</li> <li>Royal College of Physicians</li> <li>Royal Pharmaceutical Society</li> <li>Royal Society of Medicine</li> <li>UK Clinical Pharmacy</li> </ul>	<p><u>General</u></p> <ul style="list-style-type: none"> <li>Allied Health Professionals Federation</li> <li>Board of Community Health Councils in Wales</li> <li>British National Formulary</li> <li>Care Quality Commission</li> <li>Department of Health, Social Services and Public Safety for Northern Ireland</li> <li>Medicines and Healthcare products Regulatory Agency</li> <li>National Association of Primary Care</li> <li>National Pharmacy Association</li> <li>National Services division for Scotland</li> <li>NHS Alliance</li> <li>NHS Commercial Medicines Unit</li> <li>NHS Confederation</li> <li>Scottish Medicines Consortium</li> <li>Welsh Government</li> </ul> <p><u>Possible comparator companies</u></p> <ul style="list-style-type: none"> <li>none</li> </ul> <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> <li>Cochrane Cystic Fibrosis and Genetic Disorders Group</li> <li>MRC Clinical Trials Unit</li> <li>National Institute for Health Research</li> <li>Society for the Study of Inborn Errors of Metabolism</li> </ul> <p><u>Associated Public Health Groups</u></p> <ul style="list-style-type: none"> <li>Public Health England</li> <li>Public Health Wales</li> </ul>

<b>Consultees</b>	<b>Commentators (no right to submit or appeal)</b>
<ul style="list-style-type: none"> <li>• UK Genetic Testing Network</li> </ul> <p><u>Others</u></p> <ul style="list-style-type: none"> <li>• Addenbrooke's Lysosomal Disorders Unit</li> <li>• Birmingham Children's Hospital NHS Foundation Trust Lysosomal Storage Disorders Unit</li> <li>• Department of Endocrinology, University Hospital Birmingham Foundation Trust</li> <li>• Department of Health</li> <li>• Great Ormond Street Hospital Metabolic Unit</li> <li>• National Hospital for Neurology and Neurosurgery Charles Dent Metabolic Unit</li> <li>• NHS England</li> <li>• Royal Free Lysosomal Storage Disorders Unit</li> <li>• Salford Royal NHS Foundation Trust Mark Holland Metabolic Unit</li> <li>• Willink Unit, Genetic Medicine, Central Manchester Foundation Trust</li> </ul>	

NICE is committed to promoting equality, eliminating unlawful discrimination and fostering good relations between people who share a protected characteristic and those who do not. Please let us know if we have missed any important organisations from the lists in the matrix, and which organisations we should include that have a particular focus on relevant equality issues.

***PTO FOR DEFINITIONS OF CONSULTTEES AND COMMENTATORS***

## **Definitions:**

### Consultees

Organisations that accept an invitation to participate in the appraisal; the company that markets the technology; national professional organisations; national patient organisations; the Department of Health and the Welsh Government and relevant NHS organisations in England.

The company that markets the technology is invited to make an evidence submission, respond to consultations, nominate clinical experts and has the right to appeal against the Final Appraisal Determination (FAD).

All non-company consultees are invited to submit a statement<sup>1</sup>, respond to consultations, nominate clinical or patient experts and have the right to appeal against the Final Appraisal Determination (FAD).

### Commentators

Organisations that engage in the appraisal process but that are not asked to prepare an evidence submission or statement, are able to respond to consultations and they receive the FAD for information only, without right of appeal. These organisations are: companies that market comparator technologies; Healthcare Improvement Scotland;; related research groups where appropriate (for example, the Medical Research Council [MRC], National Cancer Research Institute); other groups (for example, the NHS Confederation, NHS Alliance and NHS Commercial Medicines Unit, and the British National Formulary.

All non-company commentators are invited to nominate clinical or patient experts.

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<sup>1</sup> Non company consultees are invited to submit statements relevant to the group they are representing.